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ABSTRACT

This study sought: (1) to develop and collect evidence of reliability and validity for self-report instruments to measure cognitions about the experience of having a child with a disability; and (2) to examine the relationship of these cognitions with measures of stress and well-being among parents of children with disabilities. Cognitions included causal attributions, perceptions of mastery/control, social comparisons, and positive contributions. The study surveyed 1270 parents representing 893 families of persons with disabilities. Compared to other research, results indicated weaker relationships between characteristics of the child and parent and measures of stress. Results suggest that the way that parents think about having and raising a child with a disability is as good a predictor of how much stress they experience as more objective aspects of their situation such as child's age or family income. The study provided moderate support for S. E. Taylor's theory of cognitive adaptation, especially in regard to the role of making social comparisons and construing positive benefits with adjustment. However, little evidence was found to show that causal attributions and perceptions of control serve to reduce stress or bolster well-being. A description of the Family Perceptions Research Project which undertook the study is appended. (29 references.) (JDD)

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DO SOMETHING ABOUT IT -- THINK! COGNITIVE COPING STRATEGIES AND STRESS AND WELL-BEING IN PARENTS OF CHILDREN WITH DISABILITIES

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Do Something About It -- Think!
Cognitive Coping Strategies and Stress and Well-Being in Parents of Children With Disabilities

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Introduction

Several years ago, Patty Gerdel, the mother of a child with cerebral palsy in Topeka, Kansas, wrote what was, for us, a seminal paper. Although the paper was brief and did not conform to professional standards for empirical support, it expressed poignant insights into the discrepancy between research findings and the experiences of families of children with disabilities. The paper was entitled, "Who Are the Researchers and Why Are They Saying These Horrible Things About Me?"

In this cogent paper, Gerdel (undated) reviewed the findings of researchers who concluded that families of children with disabilities tended to be dysfunctional, highly stressed, and at-risk for failure as families, often incapable of meeting the needs of their children with disabilities or other family members. Drawing from her own experiences and those of many other families she had come to know from a local mutual information and support program for families of children with disabilities, Gerdel asserted that these conclusions were unwarranted. Instead, it was her observation that these families were similar in most respects to other "normal" families, with their share of difficulties, certainly, but with joys, as well. To illustrate her point, Gerdel offered the following "statistics:"

85% of the time I feel pleased with my child.

17% of the time I question my world and wonder why I've been put in this position.

22% of the time I wish society could be a little more understanding of my child's needs.

8% of the time I get tired of continually assisting my child in doing things he could do for himself.

91% of the time I feel I could burst with pride over my family and the love we share.

100% of the time I take one day at a time (p. 5).

Dr. Ann Turnbull, professor of Special Education at the University of Kansas, herself a mother of a son with mental retardation, and Shirley Behr, then a doctoral student at the University, concurred with Gerdel's observations and embarked on a series of studies on the positive aspects of having a child with a disability. In these studies, parents told Turnbull and Behr that not only were their families similar to other families, but that they had actually experienced benefits from having a child with a disability -- benefits they otherwise would not have experienced. Often, such expressions of benefit were regarded by others as evidence of denial or rationalization, and not as authentic accounts of personal experience.

About that same time, psychological researchers were writing about cognitive strategies individuals use when coping with such stressors as cancer, accidents, rape, and chronic illness. From clinical studies, they reported that certain cognitive strategies seemed to be associated with better adjustment to the stressful event. Not surprisingly, one of these strategies was construing positive benefits from the stressful event. Viewing what we began calling "positive contributions" as a <u>strategy</u> for adjusting to stress, rather than as a <u>result</u> of (unhealthy) psychological or emotional/cognitive

processes, raised questions about the relationships of positive contributions to stress and well-being and prompted us to ask whether other coping strategies cited in the research literature could be observed in parents of children with disabilities.

By combining the observations of these parents with observations and theoretical speculation of researchers, we designed and conducted the Family Perceptions Research Project to develop instruments to measure the use of four cognitive coping strategies and to investigate their relationship to measures of stress and well-being. This paper is a report of some of the findings of the study.

Rationale

Direction for theory, research, and practice related to families of children with disabilities over the past 50 years has been influenced by public policies, sociological and scientific trends, and world events. During the 1930's and 1940's children with disabilities (particularly mental retardation) were presumed to have a negative effect on their families. Stereotypes emerged that portrayed parents of children with disabilities as likely to be unable to function as a cohesive family unit; unable to face reality; unlikely to accept or support treatment programs prescribed by professionals; generally ill-equipped to meet the demands imposed by their child's disability; having negative feelings about the added burdens and limitations they faced; and having chronic sorrow, constant anxiety, and continuing disappointment. Parents were advised frequently to institutionalize their children with mental retardation and to seek psychological counseling for themselves. Parents of children with emotional disabilities and autism were believed to be responsible for their children's disabilities.

Following World War II and the Korean War, sociologists began to study how families reacted to stress arising from separations from and reunions with their returning servicemen. The family crisis model, ABCX, was developed by Reuben Hill (1949; 1958) as a framework for examining factors associated with the family's recovery from the disruptive effects of stress. In Hill's model, A (characteristics of the stressor event) interacting with B (the family's crisis-meeting resources) interacting with C (the definition the family makes of the event), produces X (the crisis).

The Double ABCX model (McCubbin & Patterson, 1983) later expanded on Hill's original framework to incorporate the results of longitudinal studies of American families with a father or husband held prisoner or unaccounted for during or following the Vietnam War. This model served as a framework for ascertaining which families, under what conditions, using which coping resources were best able to endure the hardships of life. The central concept of the ABCX model, family adaptation, is the outcome of the family's efforts to reach a new level of balance after a family crisis. The model accounts for the accumulation of demands already present in the family system before a particular stressful event. New demands resulting from such stressful events, as having a child with a disability, combined with demands already present, may exceed the family's capability to adapt. Unresolved stress creates continuing tension that can result in a family crisis and stress-related illnesses among family members. However, when the family is able to use existing resources and define the situation in a way that resists change in the family system, stress may not reach crisis proportions (McCubbin & Patterson, 1983, p. 10). This line of research guided the development of programs and services to help families adjust to changes in their domestic and community life.

Research in the disability field followed a parallel course beginning in the 1940's. Studies were conducted to examine the factors related to stress

among families of children with disabilities, and many of them concluded that stress is not an unavoidable outcome for families. Rather, predictions of stress are based on a combination of factors including the presence of many stressors; caretaking demands and the amount of time spent meeting them; the family's life-cycle stage; social isolation; how the family interprets their situation; and, the family's degree of integration before the birth of their child with a disability. Researchers explored practical problems which faced families and how services and programs might be designed to overcome them. Many of these studies concluded that mothers assumed the major caretaking burden for their children with disabilities, had greater stress than fathers, and experienced feelings of restriction and isolation; siblings of children with disabilities needed attention and support from service providers; parents of adults with disabilities had unique problems because of their children's unemployment status and unresolved questions about future issues; and, contacts with the service delivery system could be a major source of stress for parents.

Research on the sources of stress have focused primarily on the negative effects associated with raising children with disabilities. Studies of this nature have contributed to our understanding of families, providing valuable insights about families and family members who are most susceptible to stress. However, they fail to explain why and how stress can be avoided or overcome. Such explanations are more likely to emerge from salutogenically-oriented research on factors which distinguish families who experience low levels of stress and high levels of well-being. The Family Perceptions Research Project was conducted to explore those factors.

Theoretical Framework

A major mission of the study was to develop instruments to measure

cognitions presented by Taylor (1983) in her cognitive adaptation theory. Such instruments are necessary for gathering data about the use of the cognitions, their underlying dimensions, and their relationships to successful family outcomes.

Cognitive adaptation theory was proposed to explain research findings that suggested that survivors of such threatening events as cancer, accidents, strokes, and rape, adjust to these events and their outcomes by engaging in distinctive cognitions about the events and themselves. Some individuals appear to not only regain their previous level of adjustment, but actually benefit from their experiences. The nature of the "threatening event" in our study was the presence of a family member with a disability.

Taylor proposed that adjustment to threatening events is facilitated by three dimensions of cognitive adaptation: a search for the meaning of the event, enhancing self-esteem, and establishing mastery over the event, in particular, and over one's life, more broadly. We hypothesized that four cognitions would be associated with the process of adjustment: (1) Attributing a cause for the event would contribute both to a sense of mastery and to a sense of meaning or purpose; (2) Gaining an illusion of control over the event and outcomes would contribute directly to a sense of mastery or control of the individual's environment; (3) Making social comparisons would serve to enhance self-esteem; and (4) Construing positive benefits from the event would contribute both to a sense of meaning and would enhance self-esteem. (It is unclear whether these cognitions represent Hill's (1958) and McCubbin and Patterson's (1983) C Factor, the family's definition of the event or B factors, coping strategies. Taylor's theory seems to support the latter classification.) The following section of the paper is a discussion of the cognitions and instruments developed to measure them.

Causal attributions. Theory suggests that individuals who encounter a threat or aversive experience may initiate a search for the cause of that experience to establish or re-establish a sense of control (Taylor, Lichtman, & Wood, 1984) and/or a sense of the orderliness and predictability of the environment (Rothbaum, Weisz, & Snyder, 1982). Investigators have found that those who have experienced a variety of threatening events do, indeed, tend to assign a cause to the event (for example, Affleck, Tennen, & Gershman, 1984; Bulman & Wortman, 1977; Silver, Boon, & Stone, 1983). There is support for the notion that identifying a cause is an important strategy in adaptation for families who have a member with disabilities. Commentators have remarked that parents may be overly preoccupied (from the perspective of the service provider) with a search for the cause of their child's problems (Blacher, 1984), and may engage in "shopping behavior," that is, contracting with a series of professionals to conduct diagnostic evaluations on their child. Rather than a dysfunctional response based on denial, as has been assumed by some, cognitive adaptation theory suggests that identifying a cause might be an elemental part of the adaptive process. For example, Bernheimer, Young, and Winton (1983) found that mothers whose children has received a definite diagnosis (Down Syndrome) tended to experience less stress than mothers whose children had received an amibiguous diagnosis (a developmental delay of unknown origin).

Whether the specific content of a causal attribution has a relationship to positive adjustment is not clear. An individual may blame a variety of sources for an event, including oneself, other persons, the environment, God, or fate or luck. Some research suggests that self-blame is associated with positive adjustment (for example, Affleck, Allen, McGrade, & McQueenly, 1982), presumably because it serves as a basis for establishing control of the situation in the future. Consistent with this notion, other research has reported that blaming others is associated with poorer adjustment (Taylor et al.,

1984). Still other research suggests that the content of the cause is not as important as perceiving a cause (Taylor, 1983), and that identifying a cause may not be as important immediately after the onset of the crisis as it is at a later time (Bulman & Wortman, 1977; Taylor, et al., 1984). These are questions still to be resolved in both cognitive adaptation and disability research.

As part of our research activities, we developed an instrument to measure the individual's perceptions of his/her child's disability. Respondents were asked to indicate on a 4-point scale their agreement/disagreement with statements beginning with the item stem "My child's disability is because of. . ." followed by 15 potential "causes." Five dimensions were found to underlie items on the instrument:

1. Self-blame, including such causes as "my overall state of mind" and "something someone else in my family did" (respondents did not distinguish between themselves or other family members as causes);

2. Professional blame, including "something professionals did" and "an injury during my child's birth";

3. Special purpose, including "God's will" and "some special purpose";

4. Physiologic cause, including "a hormonal condition" and "a chemical imbalance";

5. Fate or chance.

Mastery/Control. Mastery involves "gaining a feeling of control over the threatening event so as to manage it or keep it from occurring again (Taylor, 1983, p. 1163). Affleck, et al., (1985) found that mothers of newborns in intensive care who believed they had greater personal control over their children's recovery tended to experience significantly less depression and significantly fewer major stress reactions, e.g., troubled dreams and

dulled sensations. Other studies have shown that parents with an internal locus of control tended to better adjusted, to seek services for their children more actively, and to participate more actively in their children's treatment programs (Affleck, et al., 1982).

Individuals may also perceive that such others as doctors, service providers, or God, have the power to influence positively the outcomes of traumatic events. Taylor et al., (1984) found that belief in one's own control and in the control of others were both significantly associated with positive adjustment. This line of research leads to the hypothesis that families of persons with disabilities who perceive the future course of a situation as controllable may tend to experience better adjustment. It also raises the question of whether the perception of who is in control -- one's self or others -- is related to adjustment.

The Mastery/Control instrument we developed asked respondents to indicate on a 4-point scale the degree of control, from "a lot of control" to "no control" they, professionals (teachers, doctors, therapists, etc.), and others (spouse, friends, relatives, etc.) had over long- and short-term outcomes in their children's lives. Four underlying dimensions were identified in the items:

1. Professional control;
2. Personal control;
3. Control by others;
4. Control over obtaining information.

Social comparisons. Self-esteem might be enhanced by comparing oneself to others. When using downward comparisons (comparing oneself favorably to others), individuals might feel better about their own situation if they judge others to be less fortunate than they on some dimension. In her studies of women with breast cancer, Taylor (1983) found that women differentially chose

their referent for comparison so they would see themselves advantageously. For example, women with lumpectomies felt better off than women with radical mastectomies, and married women with mastectomies felt better off than single women with mastectomies.

Taylor's findings are paralleled by findings in an ethnographic study conducted by Turnbull, Summers, & Brotherson (1984). Parents of children with disabilities either compared their children favorably to children without disabilities (e.g., believing their was easier to raise than the typical teenager), or compared their children's disabilities to other disabilities (e.g., grateful that their children's disabilities were less severe or, alternatively, grateful that their children's disabilities were so severe that he or she could not be aware of and hurt by community stigma and rejection).

Similar (perceiving oneself as equal to others) or upward (perceiving others as better off) might also be effective coping strategies. For example, one might select a referent who is coping well, as a source of motivation (e.g., "If she can do it, so can I"). Similar comparisons might also serve a coping function by facilitating identification with others (e.g., "We're all in the same boat"). Taylor (1983) suggests that individuals might focus relatively narrowly on an index person or group that provides them an opportunity for comparisons that result in positive coping.

Items for the Social Comparisons instrument were initially generated by using a framework in which one dimension pertained to the comparison "direction" -- downward, similar, or upward -- and the other dimension pertained to the resulting assessment of the individual's situation -- favorable or unfavorable. Items were constructed to compare the respondent's self, child, or family with others. Four social comparisons dimensions were identified:

1. Upward/Favorable Assessment, including such items as "It gives me

hope to think about other families who seem to handle their children's disabilities better than my family does" and "I feel good about my child's future when I think about others with disabilities who are doing better than my child";

2. Similar Comparison, including "My family is managing about as well as other families who have children with disabilities" and "I am getting along about as well as other parents who have children with the same disability my child has";

3. Upward/Unfavorable Assessment, including "I get discouraged when I see other parents who are coping with their children's disabilities better than I am" and "When I compare my child with other children who are doing better, I feel badly that my child isn't making better progress";

4. Downward Comparison, including "I feel fortunate that my child doesn't have as many serious problems as other children have" and "My child seems to be making better progress than others who have disabilities."

Positive contributions. Selectively attending to the positive aspects or benefits of a situation has been identified as a coping strategy (Pearlin & Schooler, 1978). Taylor (1983) labeled construing positive benefit as establishing cognitive or retrospective control of a situation. For example, deriving a sense of pride in a child's accomplishments can center around the nature of the accomplishment, the perceived innate ability of the child, or the child's level of effort. Since level of effort might be more highly valued in this culture (Lavelle & Keogh, 1980), a perception that a child with a disability is working hard to achieve even minimal gains might serve as a source of pride for families (see, e.g., Turnbull & Turnbull, 1985, for anecdotal reports that families do indeed feel a sense of pride in the accomplishments of their family members with mental retardation).

Focusing on the benefits of a situation involves the "search for a silver lining" (Venters, 1980). Researchers have found that individuals might construe positive benefits from a number of traumatic experiences, including cancer (Taylor, 1983), incest (Silver, et al., 1983), paralysis (Bulman & Wortman, 1977), and cystic fibrosis (Venters, 1980). Families of a person with mental retardation might be no exception; they have variously reported being strengthened (Wikler, Wasow, & Hatfield, 1983), learning greater tolerance (Turnbull, et al., 1984), experiencing more satisfying career redirection (Helsel, 1985), finding meaning in life, and enjoying unconditional love, among other benefits (Turnbull, 1985). A hypothesis emerging from these findings is that families who are able to identify benefits from their experience with disabilities might experience higher levels of family adjustment or well-being. Whether the specific content of or the number of benefits identified has a relationship to adjustment or well-being is unclear.

Items for the Positive Contributions instrument originated in interviews with parents of children with and without disabilities. Respondents were asked to indicate on a 4-point scale their agreement/disagreement with statements representing benefits parents might find in raising children. Nine dimensions of positive contributions were found:

1. Source of Pride and Cooperation, including such items as "(my child is a) help around the house" and "(I find) pride in (my child's) artistic accomplishments";

2. Source of Strength and Family Closeness, including "I am more accepting of things (as a result of having this child)" and "My family has become closer";

3. Source of Happiness and Fulfillment, including "(my child) is fun to be around" and "(my child) is kind and loving";

4. Source of Personal Growth and Maturity, including "I have learned to control my temper" and "I am a more responsible person";

5. Source of Learning Through Experience with Special Problems in Life, including "I have an increased awareness of people with disabilities" and "(my child) helps me understand people who are different";

6. Source of Career/Job Growth, including "(my child) gives new perspective to my job" and "(my child) makes me more realistic about my job";

7. Source of Expanded Social Network, including "(I have) expanded social contact with other parents" and "my circle of friends is larger";

8. Source of Awareness About Future Issues, including "I realize the importance of planning for my family's future" and "I am more aware and concerned for the future of humankind";

9. Source of Understanding of Life's Purpose, including "(my child is) a reminder that everyone has a purpose in life" and "(my child) confirms my faith in God."

Method

Purposes

Two primary purposes guided the study. The first purpose was to develop and collect evidence of reliability and validity for self-report instruments to measure cognitions about the experience of having a child with a disability. We believed that these instruments were strategic for conducting empirical studies about the use of these cognitions (causal attributions, perceptions of mastery/control, social comparisons, and positive contributions) in the population of families of individuals with disabilities. Next, we wished to examine the relationship(s) of these cognitions with measures of stress and well-being among parents of children with disabilities. We reasoned that parents who were better adjusted to their children's disabilities would report lower levels of stress and higher levels of family well-being. Findings from

the study should be useful for theory development and for training persons who provide services for these families to recognize these cognitions as evidence of efforts at coping.

A brief description of procedures used for instrument development and for obtaining the sample for the study can be found in the Experimental Approach section of the Family Perceptions Research Project abstract, attached. This portion of the report is a description of the sample and results of statistical analyses.

Sample

The approximately 1270 respondents represented 893 families of persons with disabilities in 34 states of the United States. In 42 percent of the families, both mothers and fathers responded, and in one-respondent families, most of the respondents were mothers. Overall, 34 percent of the respondents were fathers. Ages of children with disabilities ranged from less than one year to over 50 years, with a mean of 13.3 years. 61 percent of the children's disabilities were rated by parents as mild or moderate, and 39 percent were rated as severe or profound.

Instrumentation

Measures used in the study were related to characteristics of the child with the disability, characteristics of the parents, measures of the four cognitions described above, and measures of stress and family well-being.

Child's Characteristics:

a. Severity of the child's disability, rated by the parent mild, moderate, severe, or profound;

b. Child's age, in years;

c. Child's gender.

Parent's Characteristics:

a. Parent's gender;

b. Total family income, in seven categories ranging from "less than $5000" to "$50,000 and over";

c. Parent's marital status, married and not married;

d. Religiosity, in four categories ranging from "very religious" to "not religious at all".

Cognitions:

Factor scores for the dimensions identified for causal attributions, mastery/control, social comparisons, and positive contributions. To obtain factor scores, principal components for the instruments were orthogonally rotated; scores were calculated by Bartlett's method (Gorsuch, 1983).

Stress:

Measures of stress from two scales measuring different aspects of stress were derived from the Brief Stress Inventory (Preventive Measures, Inc., 1987). The Overall Stress scale asked respondents to indicate how much stress they were experiencing in their lives in general and in their work and personal lives. Responses were given on a 5-point scale from "Almost none" to "Very much, an extreme amount." The second measure of stress, the Frustrations scale, is based on the "hassles" conceptualization of stress promoted by researchers associated with Lazarus (DeLongis, Coyne, Dakof, Folkman, & Lazarus, 1982; Kanner, Coyne, Schaefer, & Lazarus, 1981) and reflects the perspective that "stress" results from the accumulation of smaller stressors. Respondents were asked to indicate the frequency of experiencing 15 common stressors. Responses were recorded on a 5-point scale from "Never or almost never" to "Almost always." Scale means were used in the analyses.

Family Well-Being:

Two different measures of family well-being were employed in the study. The first -- Satisfaction with Family Relations -- was obtained from the BSI, and conformed to the same scoring format as the measures of stress. The second measure of family well-being was the Family APGAR (Smilkstein & Moore, 1988). The APGAR is a five-item scale measuring different aspects of well-being in family life, and yielded scores ranging from 0 to 20. Higher scores indicated higher levels of well-being.

Analyses

The measures described above were used in a series of hierarchical regression analyses to examine the relationships between the predictors (children's characteristics, parent's characteristics, and cognitions) and the criteria (stress and family well-being). The technique enabled the investigation of relationships between sets of predictors and the criteria after other variables had been accounted for. For example, at one step in the analysis, we wished to determine how much variance in stress might be explained by characteristics of the parent after characteristics of the child had been taken into account. Since the method has been used extensively by other investigators in the field of families and disability (e.g., Friedrich, Wilturner, & Cohen, 1985; Bristol, 1987; Bristol, Gallagher, & Schopler, 1988), we believed that its use would enable the ready comparison of our results with those from other studies.

The analyses were conducted by examining how well a sequence of sets of predictors predicted stress and family well-being. The sequence was modeled after one used by others (Friedrich, et al., 1985) and consisted of the following steps: (1) Characteristics of the child; (2) Characteristics of the parent; and, (3) Measures of cognitions. Specific predictor variables included within the steps are described in the Instrumentation section, above.

Results

Results from the analyses are summarized below under the headings of the criterion variables.

Overall Stress

In the analysis of scores on the Overall Stress scale, the child's characteristics accounted for 3.1 percent of the variance ($p<.05$), the parent's characteristics accounted for another 1.6 percent ($p<.05$), and the parent's cognitions accounted for 7.8 percent more ($p<.05$), for a total of 13.3 percent ($p<.05$).

Parents who reported lower levels of stress: (a) had older children; (b) were married; (c) were more likely to make Upward/Favorable and Downward social comparisons; (d) were less likely to make Upward/Unfavorable social comparisons; (e) were more likely to perceive their children to be sources of acceptance and family closeness; and, (f) were less likely to perceive their children to be sources of personal growth and maturity or understanding of life's purposes.

Frustrations

The child's characteristics accounted for 1.8 percent ($p<.05$) of the variance in scores, the parent's characteristics accounted for an additional 10.3 percent ($p<.05$), and the parent's cognitions accounted for 13.2 percent ($p<.05$) more. The entire prediction model accounted for 25.3 percent ($p<.05$) of the variance in Frustrations scores.

Parents who reported lower levels of frustrations: (a) had older children; (b) had higher incomes; (c) were more likely fathers; (d) were more likely to attribute the cause of their children's disabilities to physiological causes; (e) were more likely to make Upward/Favorable or Downward social comparisons; (f) were less likely to make Upward/Unfavorable social compari-

sons; and, (g) were less likely to perceive their children to be sources of awareness of future issues or understanding of life's purposes.

Family APGAR

The child's characteristics accounted for less than 1 percent (n.s.) of the variance in family well-being as measured by the APGAR. The parent's characteristics accounted for 5.0 percent ($p<.05$) more, and the parent's cognitions accounted for 25.6 percent ($p<.05$) more, for a total of 31.6 percent ($p<.05$).

Parents who reported higher levels of family well-being: (a) had older children; (b) were more religious; (c) were more likely to make Upward/Favorable social comparisons; (d) were less likely to make Upward/Unfavorable social comparisons; (e) were less likely to attribute the cause of their children's disabilities to physiological causes; (f) were more likely to have a sense of personal control over outcomes for their children; (g) were more likely to perceive their children to be sources of awareness of future issues, expanded social networks, and acceptance and family closeness; and (h) were less likely to perceive their children to be sources of understanding of life's purposes.

Satisfaction with Family Relations

The child's characteristics accounted for 3.6 percent ($p<.05$) of the variance in Satisfaction with Family Relations, the parent's characteristics accounted for 8.0 percent ($p<.05$) more, and the parent's cognitions accounted for an additional 23.0 percent ($p<.05$), for a total of 34.6 percent ($p<.05$).

Parents who reported higher levels of satisfaction with family relations: (a) had older children; (b) had higher incomes; (c) were more likely to be fathers; (d) were less likely to attribute the cause of their children's disabilities to physiological causes; (e) were more likely to make Similar or Downward social comparisons; (f) were less likely to make Upward/Unfavorable social comparisons; (g) were more likely to perceive their children to be

sources of expanded social networks, happiness and fulfillment, acceptance and family closeness, and pride and cooperation; and (h) were less likely to perceive their children to be sources of understanding of life's purposes.

Discussion

Several observations about these results are compelling and have implications for theoretical conceptualizations of stress, particularly when applied to such unique populations as parents of children with disabilities, for the need for exploring the relationships between cognitions (and cognitive coping strategies) to stress and well-being, and for clarifying the relationship between stress and well-being.

First, even though the entire set of predictors accounted for a significant proportion of variance in Overall Stress and Frustrations scores, there remained over 86 percent and 74 percent, respectively, of the variance to be explained. Obviously, other aspects of the lives of parents of children with disabilities are much more powerful in determining how much generalized stress they experience. These results diverge from those reported by other investigators who have found much stronger relationships between characteristics of the child and parent and measures of stress than were shown in this study. We believe that these differences in results can be explained by differences in conceptualizations of stress and, consequently, instrumentation. Many investigators have employed as a measure of stress the Questionnaire on Resources and Stress (QRS) (Holroyd, 1974). The QRS and other similar measures were designed specifically for use with families of children with disabilities, and the items reflect the requirements of providing care of these children.

We chose <u>not</u> to use a disability-specific stress measure for three reasons. First, such measures might be redundant with child-related predictors and might artificially inflate the relationships between predictors and

stress. Second, we believe that caregiving is not, in itself, distressing. Instead, it providing care for others might result in feelings of competence, worthiness, and fulfillment.

Third, the use of disability-specific measures of stress preclude the comparison of stress among parents of children with and without disabilities.

Next, these results suggest that the way that parents think about having and raising a child with a disability is at least as good a predictor of how much stress they experience as more "objective" aspects of their situation (child's age, income, etc.). It appears that certain cognitions are more related to favorable outcomes (lower stress and higher family well-being) for parents than are others. For example, the use of Upward/Favorable and Downward social comparisons consistently made unique contributions to the prediction of criterion variables, and perceiving one's child to be a source of acceptance and family closeness, happiness and fulfillment, and expanded social networks tended to be related to favorable outcomes. Unexpectedly, other "positive contributions" -- source of understanding of life's purpose and personal growth and maturity -- were inversely related to favorable outcomes. These findings go beyond the use of cognitive coping strategies and raise questions about the content of such cognitions.

Finally, a subtle, unstated theme that pervades the "stress" literature is that stress and well-being are antithetical, and that reducing stress results in greater well-being and vice-versa. Our findings do not support that assumption. Considerably more variance was explained by identical prediction models for the two measures of family well-being than for the measures of stress. While some variables made significant unique contributions to the prediction of both types of measures, there were substantive differences. These results emphasize that stress and well-being are not, simply, opposites,

but that they co-exist and, perhaps, are related to different cognitive processes.

Summary

The study was conducted to develop instruments to measure the use of four cognitions associated with adjustment to threatening events and to investigate the relationship between those cognitions and stress and family well-being of parents of children with disabilities. Results provided moderate support for Taylor's (1983) theory of cognitive adaptation, especially in regard to the role of making social comparisons and construing positive benefits with adjustment. However, little evidence was found to show that causal attributions and perceptions of control serve to reduce stress or bolster well-being. Finally, questions were raised about appropriate conceptualizations of stress in general and for parents of children with disabilities, the need for more investigation into the role of cognitive strategies in ameliorating stress and enhancing well-being, and the relationship between stress and well-being.

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FAMILY PERCEPTIONS RESEARCH PROJECT

March, 1990

Following is a summary of the background, purpose, experimental approach and implications related to the Family Perceptions Research Project. This project is funded under a three year field-initiated research grant from the National Institute on Disability and Rehabilitation Research (NIDRR). The scheduled date for completion of the project is September 15, 1990.

Background

Empirical studies on the impact of children with mental retardation on their families suggest that families are extremely variable in their responses to their children and the challenges surrounding them. Recent research has focused on identifying variables that distinguish families who are resilient in the face of these challenges, from those who are less successful. Many of the more obvious demographic variables (e.g., SES, single parenthood, level of severity of the child's disabilities) have been found to be less predictive of resilience than other less tangible variables, such as social support and marital quality. One set of variables which may be related to resilience and successful coping is the degree to which family members utilize cognitive coping strategies to alter their perceptions about themselves, their children, and their situations in general.

Research in the area of cognitive adaptation suggests that the ability to perceive positive benefits, to compare oneself favorably with others, to identify a perceived cause, and to perceive that one has mastery or control over the situation, are related to positive coping. Use of these cognitive coping strategies allow for changes in perceptions or definitions of a situation to make that situation seem less stressful. Positive coping is demonstrated by lower levels of depression and stress and more active involvement in service programs, among other outcomes. However, research studies along this line have primarily been conducted among populations other than families of children and adults with disabilities (e.g., accident victims, cancer patients, stroke victims). Further, few attempts have been made to develop psychometrically validated instruments to measure the degree to which individuals may use specific coping strategies. Thus, very little is understood about: 1) the underlying dimensions of these strategies; 2) the degree to which they may be differentially useful to individuals; and, 3) the patterns of differences between men and women in the use of these strategies.

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The Beach Center on Families and Disability is a rehabilitation research and training center devoted to supporting the inherent strength of families over the life span. The center is funded by the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, United States Department of Education, under the supervision of Naomi Karp, project officer; and by various academic and research units of the University of Kansas, under the co-direction of Ann P. Turnbull and H. Rutherford Turnbull, III.

Purpose

The overall purpose of this project was to develop and validate instruments to measure self-reported use of the four cognitive coping strategies described above and to examine their relationship to outcome measures of family well-being and stress among parents who have children with disabilities, particularly mental retardation. Specifically, the project has completed the following major objectives:

1. Developed self-report measures of positive contributions, social comparisons, causal attributions, and mastery/control, and conducted factor analyses to identify the underlying structures of these constructs.

2. Conducted a validation study of the revised measures among a national sample of parents (N=1300) who have sons or daughters with disabilities across the life span (birth through adulthood) to determine relationships of these measures to social desirability and to measures of stress and family well-being.

3. Conducted supplementary post-hoc analyses on the data among respondents who were parents of younger children, ages birth to six, with mental retardation, to identify: a) patterns of response on the coping measures as distinguished from respondents at later life cycle stages, and b) possible differences between mothers and fathers in self-reported use of these coping strategies and in their relationship to measures of stress and family well-being.

Experimental Approach

Phase 1: Factor Analysis. During this phase of the study, completed in Year 1 of the project, a review of the literature was conducted to identify hypothesized theoretical dimensions underlying the four types of coping strategies. Items based on the hypothesized dimensions were generated for three of the four instruments. The Positive Contributions instrument was constructed using field-generated items gathered from interviews with parents of children with and without disabilities. The draft instruments were included in a questionnaire booklet which also included a measure of locus of control and a measure of social desirability.

The sampling plan involved selecting a mailing list of families with and without sons or daughters with mental retardation, compiled from preschools, special and regular education programs, adult service agencies and businesses, all in the northeast Kansas area. Efforts were made to select agencies serving different socio-economic and ethnic groups. These agencies were asked to select families at random from their lists and to mail a letter soliciting participation to those families. A total of 1150 families received this initial mailing; of these, 296 returned post cards expressing

interest in the study (26% return rate). A total of 268 of these respondents returned completed booklets (90% return rate); approximately half of these were families with children with mental retardation.

Each of four cognitive coping instruments was analyzed separately. Responses were submitted to principal components analyses to identify salient dimensions. The instruments were revised, based on these analyses and on analysis of item correlations with social desirability.

Phase 2: Validation Study. The revised measures were compiled in a new instrument booklet which also contained a measure of social desirability (Marlowe-Crowne Social Desirability Scale MC 10), a measure of family well-being (Family APGAR), and a measure of stress (Computerized Stress Inventory), and a demographic questionnaire.

The national study sample (N=1300) consisted entirely of families of children and adults with developmental disabilities. A sub-study was also conducted among families (N=100) of children who do not have disabilities. The ten federal regions of the U.S. served as a framework for selecting the sample. Through contact with colleagues in each region, a total of 33 preschool, special education, and adult mental retardation services agencies agreed to participate in the study. Each agency was asked to select a random sample of families to receive a packet soliciting their participation; a total of 3,187 families received the initial mailing.

Internal consistency of instruments was assessed by use of Chronbach's alpha procedures. Test-retest reliability was determined by re-administering the instruments to a random sample of 100 respondents (62 of whom completed the retest survey). The construct validity of the four coping instruments was analyzed by determining zero-order correlation coefficients of each instrument with each of the dependent measures. Multiple regression techniques were employed to study relationships among the various predictors and outcome measure, and group differences were analyzed through a series of analyses of variance tests.

Implications

This research will make a contribution to cognitive coping theory by further delineating and refining the dimensions of coping. Development of valid measures of the use of these coping strategies will provide a vehicle for more in-depth, quantitative investigation of this phenomenon, which has previously been studied largely through qualitative methodologies. Findings will lead to an enhanced understanding of the use of these coping strategies by families of children with mental retardation by examining the relationship of these strategies to stress and family well-being, and patterns of use of these strategies across various independent variables (e.g. life cycle stage, income, sex of parent, participation/nonparticipation in support groups).

This line of research has implications for developing interventions that assist families to enhance their use of cognitive coping strategies, as well for developing training programs to help professionals increase their understanding of cognitive coping strategies and ways to facilitate the use of these naturally-occurring processes among families of children with disabilities; and 3) future research aimed at in-depth investigation of these coping strategies among families of children with disabilities from different cultural and socioeconomic backgrounds and at different life-cycle stages, as well as among families who have family members with chronic illnesses and Alzheimer's Disease.

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